



Myositis Newsletter



THE MYOSITIS ASSOCIATION

Georgia Myositis Support Group Newsletter

~Next Meeting~ February 24, 2018

10:30am-2:00pm

Collins Hill Library

455 Camp Perrin Road, NE

Lawrenceville, GA 30043

Lunch provided by Soleo Health

Reservations are a must!

Please call Cheryle 678-386-2435

or email CheryleMiller@comcast.net

By February 16th



Volume 18, Issue 1
Winter 2018

2018
Feb 24
Apr 21
Jul TBA
Oct TBA

New Members

New member
attending in November
Bill Rutledge

Speakers for IBM

I'm so happy to announce, courtesy of **Tom Cox**, that our next few meetings will be of special interest to members with IBM. Tom has arranged some of his personal health providers to speak at our meetings. For February we have his speech therapist, **Tiffany McCusker**, who is helping Tom with swallowing issues.

In April, we have neurologist, **Dr Stephanie Palma** presenting, who is using neuromuscular Electrical stimulation in Tom's treatment.

Also, **Josh Miller** from **Bioness**, to speak soon about their neuro muscular

February's Speaker

Tiffany McCusker

Tiffany is a speech language pathologist for Northside Forsyth Hospital. She has been practicing for 12 years after obtaining her master's degree from the University of Georgia. She specializes in working in outpatient rehabilitation for disorders including stroke, brain injury, cancer, Parkinson's, and other degenerative disorders. Tiffany is a published author in the UK Journal of Disability and Rehabilitation. Additionally, Tiffany has specialty certifications in the instrumental evaluation of swallowing.

Inside this issue:

Advanced Care Planning	2
Products That Benefit	3
Useful Information	4
Pixie's Perspective	5
Let's Share	7





2018 Piedmont Healthcare Community Healthcare Class Schedule

Advance Care Planning ~ Free Classes!!

Piedmont Atlanta Hospital, April 11, July 11, October 10 (classes 11 am-noon)

1968 Peachtree Rd. NW, Atlanta Building 77, Classroom 7

Piedmont Henry Hospital, January 26 (1pm-2pm)

Deer Creek Senior Activity Center 55 McDonough St, Hampton

Piedmont Newnan Hospital, February 27, May 22, August 28, November 27

745 Poplar Rd., Newnan Conference Room #1 ((1pm-2pm)

Piedmont Fayette Hospital, January 23, April 11 July 11, October 10

Classes are at Fayette County Chamber of Commerce Room # 205(2pm-3pm)

600 W Lanier Ave, Fayetteville

Piedmont Mountianside Hospital, Education Room, February 20, July 17 (2pm-3pm)

1266 GA-515, Jasper AND

Community Center Ellijay, May 15, September 18 (1pm-2pm)

824 Industrial Blvd, Ellijay

Piedmont Newton Hospital , April 17, July 17, October 16 (1pm-2pm)

Physicians Office Building at Newton Hospital Auditorium

4181 Hospital Dr. NE, Covington





Products That Benefit

This product I can personally recommend. When my leg muscles were at their very worst, the EZ Step enabled me to climb the stairs in my house and to step on and off a curb. ~ Cheryle

EZ-Step Stair Climbing Cane

EZ-Step Stair Climbing Cane is a unique, patented, one of a kind mobility aide that makes virtually any stairway accessible to anyone who has difficulty with stairs. Using the EZ-Step reduces the range of motion required to flex the knee while ascending or descending stairs, curbs, sidewalks, swimming pools, automobiles or walk-in tubs. Because it is lightweight it may also be used as a Quad Cane. \$82.99

ShopWheelchair.com

- EZ-Step Stair Climbing Cane is adjustable from 29" to 39" with offset ergonomic handle and hand strap
- Base is made of lightweight ABS plastic
- Base measurements are 3.5" high x 9.25" wide x 9.25" long
- Offset ergonomic design
- Soft latex foam cushion grip for secure grasp
- Convenient hand strap for easy storage
- May be used either right or left handed
- Non-skid diamond shaped tread surface
- Rubber grommet feet for greater stability and security
- Base made in the USA





Useful Information and Tips

A Memo from member Kim Brooks

Please tell any whose insurance will not cover cellcept/mycophenolate or imuran/azathioprine for myositis, I found out that if you purchase the \$100/A year Sam's Club card, you can get the generics for \$40/120 pills without using any insurance.

Helpful Resources

Patient Advocate Foundation (PAF) (800.532.5274, www.patientadvocate.org) offers a range of services for patients facing medical debt crisis issues, including referrals to charity care and assistance with setting up payment plans. If a patient has a diagnosis that qualifies for copay assistance, the patient may be referred to PAF's Co-Pay Relief Program to determine eligibility.

Needy Meds (800.503.6897, www.needymeds.org) provides a prescription savings card that enables those eligible, to get discounts in certain medications at participating pharmacies throughout the nation

RxAssist.org offers a database of drug assistance programs provided by pharmaceutical companies that enable patients to receive assistance with numerous medications.

The Partnership for Prescriptions Assistance (www.pparx.org) also helps people find prescription assistance programs, as well as free or low cost healthcare clinics.

Medicare Rights Center Hotline (800.333.4114) is available to seniors or to those with a disability. When using the service, callers can learn about Medicare and other resources available to them for obtaining public health insurance. The Hotline also offers assistance for dealing with medical bills.

2018 Annual Patient Conference

Louisville KY

September 6th~ 9th



Pixies's Perspective

November 4, 2017

Ronnie Genser, Bereavement Navigators

“Making Advance Care Planning Easier with a POLST”

Physician Orders for Life-Sustaining Treatment

Ronnie Genser shared with us hard won advice about how to be prepared for difficult life events.

We all have our insurance card and list of doctors and lists of medications and a calendar of appointments, but do you know

- About the latest form the State of Georgia has created to help you be prepared so that your wishes will be implemented during a trip in an ambulance?
- The difference between a Georgia POLST and a Georgia Advance Directive for Health Care and when each is needed?
- If your loved ones truly know what your end-of-life medical wishes are as well as your end-of-life goals and values?
- Do you know have a Power of Attorney at your bank so that someone can pay bills and withdraw money while you are sick?

Ronnie has deep experience with these topics. She graciously recounted stories from her own life which highlighted the difficulties and problems a relative can face when a loved one is in the hospital or dies suddenly.

She also highlighted a series of problems including what can result, if one dies suddenly or becomes incapacitated, such as: does someone in your family know how to access your computer or WiFi? Do they know which bills need to be paid and how you do it? On a day-to-day basis, Ronnie's business Bereavement Navigators www.bereavementnavigators.com, helps clients and their loved ones prepare to handle these types of tasks, as well as many other tasks their loved ones may need to do.

The talk focused on the relatively new Georgia POLST form. Because it is signed by you (the patient) *and your physician, no lawyer is needed. You should have your doctor enter it into your medical record and make a copies for yourself This is a form you keep on your refrigerator along with your list of medications, doctors' names and emergency contact names and numbers when you have a serious medical conditions so that emergency personal and family members can easily find this information. You may also want to keep a copy in your vehicle and take a copy when you travel, in case you become ill away from home.

*Note: when someone is not mentally competent to make their own decisions about their end-of-life wishes and end-of-life values and goals, other rules apply about who can sign a Georgia POLST form for the person.

The POLST form allows patients to specify their wishes for CPR use or AND (Allow Natural Death), to allow specific comfort measures, directives and options that may not be offered in the Advance Directive unless they are *In Writing* in Part 2 of the Directive.

Continued next page





Pixie's Perspective, continued

As of January 1, 2016, Medicare is required to pay for 2 separate half hour consultations with your physician to discuss Advanced Care Planning, .consisting of sharing your particular values and goals for end of life care. (I hope this great service will not be on the U.S. Government's 'chopping block' soon)

Did you know that according to Georgia LAW, emergency medical personnel, are required to do everything possible to sustain life if you are not breathing and are in an ambulance, regardless of what is stated in your Georgia Advance Directive for Healthcare. However, **a POLST is a Medical Order**, which legally allows medics to follow your treatment preferences. It works **WITH** the Advanced Directive and often before the Directive can be used as it is a medical order..

Ms Genser also recommended a small (88 page) \$7.00 paperback book titled **Hard Choices for Loving People** by Hank Dunn. It can be ordered from Amazon. This booklet explains feeding tubes, nutrition mechanical ventilation and things like palliative care, and what your options are.

To get a copy of the Georgia Advance Directive for HealthCare, go to : <http://aging.dhs.georgia.gov/publications-0>> and scroll down to Elder Support

There is a national POLST Paradigm website <www.polst.org/advance-care-planning/how-does-polst-work>

Or go to <http://polst.org/programs-in-your-state/>>

Or <http://www.polst.org/advance-care-planning/polst-and-advance-directives/>

There was so much more in Ronnie's presentation, than I can relate in this brief article. It is difficult to know which specific topics need to be discussed by family members and caregivers with a patient because each case, each situation is so vastly different and each solution and wish is so personal. I hope we can spread the word about this important resource and the need for this form in each household.

Ronnie of Bereavement Navigators, (404) 843-9640,

is also able to help people find such things as :

- Free services that help families find nursing homes and assisted living homes that fit your needs
- Find a Geriatric Care Manager for the medical component of patient care, whether in the hospital or for home care
- Help for understanding the Medicaid process
- Help with setting up a spreadsheet that keeps all the information a family member might need to know about bills, insurance, medications, location of social security info and birth certificate



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THE MYOSITIS ASSOCIATION

www.myositis.org



MAY IS



MYOSITIS AWARENESS
MONTH

We share!

If you have experience with a mobility aid, information on insurance, doctors or medication, please pass the information to me and I will post it in the next issue so that other members can benefit from your knowledge.

We are always looking for speakers, so if you see someone who you feel would be an interesting speaker, ask them if they would make a presentation.

~ Cheryle